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Barbara F. Sharf 10/13/99  
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## Introduction

October, National Breast Cancer Awareness Month, is a particularly appropriate time to reflect upon the impact of mass media communications on public perceptions of this disease. During this time, newspapers, magazines, radio and television programs, and other forms of media report in abundance about treatments, prevention, early detection, and stories of survivors. The themes, implicit arguments, language, and strategies of these mass media accounts are the subject matter of this study. Its purpose is to assess the ways in which popular mass media play a significant role in constructing the sociocultural meanings embedded in the public's understanding of breast cancer as a societal problem, a disease, and a personal illness experience. The scope of the work includes four major phases: 1) an historical investigation of how breast cancer has been publicly depicted in popular print media over the thirty-year period of 1965-1995; 2) an analysis of how four current controversies regarding diagnosis, risk assessment, and prevention have been presented in popular print media over the past five years; 3) an examination of the implications of entertainment television having appropriated breast cancer as subject matter; and 4) a meta-analysis of the sociocultural impact of popular depictions in terms of individual citizen decision-making.<sup>1</sup>

## Body

### Scope of Work for Year 2

Work completed during Year 2 includes a second portion of the first phase, i.e., the decade of 1976-1985 of the historical overview, and two of the four controversies that comprise the second phase, analysis of print representations of four decision-making controversies related to breast cancer. Each of these separate components will be described in this section, including detailed explanations of findings.

### Assumptions and Methods

The underlying premise of this research is that how mass media construct breast cancer for the public--its most prominent themes, controversial issues, memorable dramas and stories, and possible courses of action--affects how individual citizens become aware of, comprehend, and make decisions about breast cancer-related matters. The study relies on the use of critical-interpretive analysis (Janesick, 1998; Lindlof, 1995; Rabinow & Sullivan, 1987) of verbal content in order to answer questions of "what," "how," "why," and "with what effects." The interpretive aspect of the research necessitates the centrality of the investigator's judgment, based on evidence grounded within the discursive materials examined.

**Phase 1, Part B.** For the historical overview portion of the project, the critical-interpretive process employed includes five elements: a) identification of thematic categories, comparing the emphasis given within the array of categories at various time

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<sup>1</sup> For purposes of clarity, the four phases, as described here, are a simplified version of the more detailed tasks that were enumerated in the original Statement of Work

intervals in order to assess how topic emphases change over time; b) identification of major public narratives, images, and metaphors that help to translate abstract and difficult biomedical matters in personal terms that draw the public's attention, provide motives, and coalesce attitudes; c) identification of underlying value-based ideologies in order to explicate the moral premises and arguments implicit in these media accounts; d) placement of issues specific to breast cancer within broader social/cultural/political/ legal contexts of the time; and e) assessment of how media constructions of breast cancer may influence individual citizen choices and decision-making.

In last year's annual report, a preliminary analysis of the second decade, 1976-1985, was briefly summarized. Since that time, a more complete analysis was accomplished, which included review of 427 source materials (186 magazine articles, 241 newspaper articles; see References for 1976-1985). As in the previous decade, magazine articles were identified through the use of *The Reader's Guide to Periodical Literature* under the category of "breast cancer." Newspaper articles were identified through the indexes of the *New York Times* and the *Chicago Tribune*. As we did in Year 1 of the grant, the principal investigator and the research assistant read through each article identified, taking notes and coding the article for content. In addition to investigators' notes, several articles were copied because it was not possible to summarize all the content, or to adequately capture the style of writing or visual components. For the most part, the coding scheme devised for the prior decade was able to be used, though four categories--activism, breast health, criticism, and social impact--were added to better reflect the content in the popular press (see Appendix A for coding categories and periodicals by category) during this time period.<sup>2</sup> When review of all articles for this decade was completed, the two investigators exchanged notes and copied articles to gain familiarity with the materials they had not yet read and to double-check coding. In the few cases in which there were differences about how to code a particular piece, the differences were discussed until a mutually satisfactory conclusion was reasoned through, a process integral to the interpretive approach. Also discussed were apparent differences in emphases among types of periodicals. After all articles had been reviewed and content-coded, I conducted a rhetorical analysis, describing and evaluating the media themes of this decade, as reported in the Results section to follow.

**Phase 2.** Two of four current controversies, efficacy of mammography and post-menopausal hormone replacement therapy, were reviewed and analyzed during Year 2. Primary source materials for the past five years (1993-1999) were procured via on-line indexes: the Ibis/Ovid version of the *Wilson's Select Reader's Guide to Abstracts On-line* for popular magazines and the OCLC *First Search Newspaper Abstracts* for the *New York Times*.<sup>3</sup> Several of the articles (especially in the bibliographic search for HRT) were eliminated on the basis of abstracts that indicated they were not on-target for the

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<sup>2</sup> Multiple codes were used in several instances because of the range of issues covered in the article.

<sup>3</sup> Originally, I had planned to include the *Chicago Tribune* as well, as had been done in Task 1. A bibliography from this newspaper's on-line index was also prepared for each of the two topics, but after a partial examination of the articles, I determined that a) there was a good deal of repetition between the two newspapers being studied and b) the *New York Times* appeared to have the more thorough coverage of the topics. On this basis, I decided to eliminate the *Chicago Tribune* from this portion of the project.

current study. Altogether, 175 primary sources were examined (mammography: 40 magazine articles, 52 newspaper articles; HRT: 66 magazine articles, 17 newspaper articles). Additionally, a few secondary sources were used (see References).

The unifying theme of Phase 2 is to investigate how the popular print media depict dilemmas in citizen decision-making in regard to breast cancer-related issues. In the case of mammography, the controversy has been centered on when routine screening should begin and how frequently should screening occur. For hormone replacement therapy, uncertainty has been concentrated on whether and to what degree taking estrogen and related hormones during and after menopause will increase the risk of getting breast cancer. Because this task differs in nature from Phase 1, the coding categories used in the historical overview are not pertinent to the Phase 2 examination. In order to focus these analyses on decision-making dilemmas, the principal investigator and research assistant used a note-taking schema for each article that included the following categories:

- Decision-Making Choices (What are the available choices?)
- Confusing, Ambiguous, or Contradictory Evidence (How does information supporting each alternative complicate or confuse decision-making?)
- Significant Word Use/Figures of Speech/Pictorial or Word Images (What are key words and/or images used to present the dilemma and possible solutions? Do such elements tend to predispose readers to a particular point of view?)
- Covert or Overt Recommendations (Does the author/article make an explicit recommendation on how readers should resolve the decision-making dilemma? If not explicit, is there an implicit course of action emphasized?)
- Meta-Narrative (Is this particular article reflective or constituent of a larger story, drama, repeated set of themes or argument that communicates a specific perspective on the topic?)

It was my hope that following this format would help to abbreviate the task of note-taking and facilitate analysis. In retrospect, it is apparent that it did not accomplish the former objective though it probably contributed to the latter. While these same issues certainly need to be kept in mind, the inflexibility of this outline will probably be eliminated with the remaining two controversies. Although there was no need to double-check coding, as in Phase 1, the principal investigator and research assistant have continued the practice of exchanging notes and articles, and discussing questions and interpretations of the data.

## **Results and Discussion**

### **Phase 1, Part B. Historical Overview: The Transition to Consumer Responsibility, 1976-1985**

Though the controversies, changes, and events during this second decade were not as publicly dramatic as those that occurred in the preceding ten years, there was a distinct and meaningful, even if subtle, shift from an emphasis on patient choice to that of consumer responsibility. My analysis yielded the following themes.

*The rhetoric of scientific progress, continued.* Popular periodicals carried the news of successive medical successes which, taken as a whole, changed the societal perception of

breast cancer from an imminent death sentence to a chronic disease with which people could live for a lengthy period of time. The previous controversy about the superiority of radical mastectomy had subsided in less than five years; modified radical mastectomy was now accepted as standard treatment. Biomedical innovations included positive results of clinical trials with chemotherapy (including drug combinations, such as F-A-C), radiation therapy, and hormonal therapies. In addition, advances in surgical reconstruction provided women with the option of living with less disfigurement. Though these changes represented genuine and admirable progress in the treatment of breast cancer, the media reports of these positive findings was done with hyperbolic language of optimism, asserting that the ongoing battle with cancer might be close to a resolution. Looking back to this time period is instructive, as we have recently witnessed a similar round of hopeful prognostications (e.g., cover stories of *Newsweek*, *Time*, and *U.S. News & World Report*, May 18, 1998). The exaggerated rhetoric, thus, raises false hopes and diminishes the rightful significance of scientific progress.

***Simultaneous doubts about medical wisdom.*** Even as medical triumphs were touted, there appeared in popular media an increasing number of critiques of breast cancer research and policy. Some of these were editorial criticisms, but others appeared in narrative formats, with physicians cast in the role of antagonists, rather than heroes. Additionally, the biotechnological advance of mammography suffered a major public setback. Mammography had gained a great deal of attention by the end of 1974 when First Lady Betty Ford's breast cancer was front-page news and American women's interest in early detection escalated almost overnight. A collaborative effort between the ACS and the NCI resulted in a national network of mammography centers with a fanfare of publicity. However, in the following decade information came to light that the radiation doses absorbed during mammographic examination could be life-endangering, rather than life-saving. Furthermore, from a retrospective study of mammography efficacy came the horrible news that a significant cohort of women had suffered unnecessary mastectomies due to false positives. In short, despite scientific progress in detecting and treating breast cancer, the credibility of medical science and physicians was increasingly under attack.

***Social context: Sex, inner beauty, and activism.*** While the cultural revolutions of the anti-war movement, feminism, and consumer rights shaped the emergence of breast cancer as a social health issue in the preceding decade, the societal context of the late seventies and early eighties provided a somewhat different sort of backdrop. In women's magazines, extended special features on breast health appeared. Within these features, the cosmetic breast was increasingly visualized and discussed in terms of beauty, sexuality, and good health; information on breast cancer, framed as important but a definite deviation from the generally upbeat messages, appeared as a smaller sub-feature. Simultaneously, the attention given to the sexual allure of the breast contradicted with the philosophical argument being promulgated that femininity and personhood are attributes independent of the physical breast. The patient activism that had begun in the late sixties and early seventies, continued to flourish and develop. At the personal level, breast cancer activism resulted in the proliferation of social support organizations and life style options for women with the disease. At the public level, activism was starting to play an



important role in affecting health care policy and treatment standards, e.g., NIH endorsement of a two-step process, separating biopsy from breast excision. The personal narratives of survivors that now appeared in the popular press regularly featured women protagonists who were upbeat and proactive, in contrast to the more passive victim/patients of the previous decade.

***The rhetoric of responsibility.*** Whereas the major public controversy in the previous decade was the struggle to allow patient choice in breast cancer treatment, there was now a subtle shift, reflected in mass media, from *patients* gaining choice to an assumption that *consumers* would be responsible for decisions affecting their health and the care they received. Increasingly technical, complex knowledge was being expected for women to know and to apply; for instance, women's magazines published primers on mammography that included ranges of radiation strengths with the intent that women consumers would check on safety requirements at local facilities before submitting to a check-up. This theme of patient/consumer responsibility was leading down a road that provided more options, but with greater degrees of ambiguities in terms of making decisions. More and more the language and scenarios proposed in popular media moved the burdens, as well as the rights and privileges, of medical decision-making to consumers, and did so without highlighting possibilities for better partnerships in decision-making between the lay and medical communities.

#### **Phase 2, Part A. Current Controversies related to Citizen Decision-Making and Breast Cancer: The Efficacy of Mammography Screening**

As noted in the previous section, mammography as the main biotechnological tool in detecting breast cancer for the past twenty-five years has been plagued by problems and suspicions almost since its introduction in the sphere of public health through massive breast screening. Though the dangers of radiation that worried the NIH and the public in the late seventies and early eighties has been reduced to the point of being non-problematic, throughout the early nineties a dilemma was brewing as to what the optimum age is for setting national guidelines for baseline examinations and routine screening thereafter. Previous to this time period, recommendations had been given for various ages between thirty-five and fifty. Such guidelines are important not only in terms of giving a coherent message to women, but also for cueing third party payers, such as Medicare and Medicaid, private insurance companies, and managed care organizations as to when mandatory payment for breast screening is imperative.

The American Cancer Society has been consistent in supporting routine annual or biannual mammography for women forty and over, fearing deviations from that message will undermine more than two decades of public health campaigning. When the NCI determined in 1994 that scientific evidence did not warrant routine annual screening until after age fifty, the breach between the two "cancer establishment" organizations became problematic, culminating in a very public controversy in 1997, during which the NCI broke ranks within itself. The dispute was settled through an apparently political, rather scientific, process--an event that raises questions about the credibility and seemingly arbitrary nature of screening guidelines, as well as the significance of issues that were ignored while all the attention went to the question of women between forty and fifty

years old. What follows is a brief summary of the analysis of themes that emerged from reports in the popular media over the past five years.

***A clash of rhetorical visions: Who determines the greater good?*** The position of the American Cancer Society was supported by the American College of Radiology which represented its practitioners as being most concerned with women's health and preventing early mortality. This stance was in apparent contradiction to the epidemiological evidence amassed by the NIH, leading them to the conclusion that the number of breast cancers discovered through mammography for women between forty to fifty years old did not support routine screening for this age group, though women at higher risk, in consultation with their doctors, might wish to undergo this diagnostic procedure. Though the NCI had its own prominent supporters, including editorial approval in *JAMA*, its lack of support for mammography for younger women left it open to being cast as insensitive to the well-being of women.

***Saving money vs. making money.*** Obviously, participants in each of the rhetorical visions were convinced that they were doing the right thing. Just as predictably, suspicious motives were ascribed by both sides to those who believed differently. A prominent incentive attributed to the NCI guideline was the cynical notion that those who discouraged early mammograms had an economic purpose, to save health care dollars at the expense of women's lives. On the flip side, radiologists stood to profit economically from doing more mammograms. Furthermore, big companies, like GE and DuPont, which manufacture mammogram equipment, were accused of packaging corporate ads like public service announcements aimed at women.

***An uneasy alliance between politics and science.*** Criticism of the NCI's position came from many quarters, including a Senate resolution in support of mammograms for women in their forties, inducing the NCI Director to appoint a blue ribbon committee to review the policy and supporting evidence. When the specially-appointed group of experts publicly announced agreement with the established policy, the Director made an independent, contradictory decision to reverse policy, a move that was later endorsed by President Clinton. The apparent influence of politics and public opinion on national health policy, led to a renewed firestorm of published criticism regarding the compromise of scientific judgment. This front-page drama leads to many questions affecting women's decision-making about when to begin mammography. What sense are consumers to make of conflicting experts, who review the same studies and arrive at differing conclusions? While many women may feel it is more to their advantage for guidelines to recommend routine screening beginning at age forty, how much confidence can they have in medical standards mediated by political influence, or in so-called scientific recommendations that vary every few years? Finally, to what degree do women consumers feel they have had a proactive role in helping to establish those guidelines?

***The untold story.*** One of the most important aspects of this analysis is the criticisms that point to crucial omissions that have gone largely unnoticed amidst the attention given to the forty versus fifty controversy. Such commentaries note that the studies upon which standards are based focus on Caucasian populations not representative of the multi-

culturally diverse population of the U.S., leading African-American and Hispanic groups to issue their own guidelines, recommending screening to begin as young as age thirty-five (in light of minority women being diagnosed at later stages, leading to higher mortality rates). Others have pointed out that the "packaging" of distinctions between groups of women based on decades is a somewhat arbitrary marker. Finally, the amount of attention given to relatively younger women between forty and fifty ignores the preponderance of women over fifty who are at even greater risk of being diagnosed with breast cancer.

### **Phase 2, Part B. Current Controversies related to Citizen Decision-Making and Breast Cancer: HRT and the Assessment of Personal Risk**

The question of whether to take hormone replacement therapy as addressed in popular media is inextricably embedded in a broader discourse concerning menopause, the process of aging, and the significance of these events in American culture. It is not coincidental that a discourse concerning HRT has come to the fore as the Baby Boom generation reaches the age of menopause. Unlike the previously discussed problems with mammography, HRT is not primarily a political issue, but one of internal personal struggle. New biotechnical advances in the development of designer estrogens signify that medicine may be on the cusp of resolving the controversy of whether or not post-menopausal women should routinely take HRT, but at present the decision continues to be an extremely knotty one that all women eventually face. The issues underlying the presentation of this topic in the popular press is summarized as follows.

*Choosing among evils.* The preponderance of articles emphasized that women approaching menopause face a devilishly complicated dilemma. In effect, women are asked to choose between two potential health outcomes: avoiding an increased risk of breast cancer (by not taking HRT) versus decreasing the risk of heart disease and osteoporosis, (by taking HRT). As many publications point out, despite a full court positive press from the medical establishment about the advantages of estrogen supplements, only a relatively small fraction of eligible women end up taking and maintaining this regiment. The primary explanation offered is widespread, deeply-rooted fear of breast cancer, even if it is not well-founded. For those individuals with a pronounced family history of heart disease, osteoporosis, or breast cancer, the advantages of one option or the other are fairly clear. But for the person with a mixed family health history, the decision is a lot more complicated. There appear to be no risk-free options, and a majority of women appear to perceive breast cancer as a more severe threat, despite the publicity emphasizing that heart disease is much more prevalent.

*Questioning what is natural.* Estrogen (combined with progesterone to protect against uterine cancer) helps to relieve symptoms of hot flashes, mood swings, etc. commonly experienced during the period of menopause. However, to reap the benefits of protecting the heart and bones, as well as to maintain bodily conditions of being "feminine forever" (Wilson, 1968), a woman must continue taking HRT throughout her lifetime. An aspect of the anti-estrogen rhetoric highlighted in the popular media is that being on synthetic hormonal supplements for twenty-thirty years is not natural (an argument borne out with the reality of a 70-something woman still having hormone-induced menstruation). Often

from this rhetorical perspective, a more positive frame is projected on the natural aging process. Margaret Mead's notion of "middle age zest" is often cited and women are said to have "power surges" in lieu of hot flashes. It is out of this mindset that many women and some practitioners are searching for more natural sources of estrogens (e.g., from plants) and herbal alternatives, as well as promoting diet and lifestyle options to combat heart disease and osteoporosis in lieu of drugs. An interesting pro-estrogen retort that has received much less media attention is the argument that having extended women's life expectancy to age 80 is what is unnatural (a century ago, women rarely lived much past the menopause). This unprecedented phenomenon of longevity, thus, requires the extended protection of estrogen that preceding generations had no reason to consider.

The arguments about what constitutes "natural" is indirectly related to fears about breast cancer, but it is only a small leap of reasoning to conclude that taking unnatural synthetic hormones for an extended period could well lead to adverse effects within the female body.

***Who to believe? Determining credibility.*** Unlike the mammography controversy in which groups of medical experts aligned themselves against one another, the media report that most medical authorities agree (at least most recently) that the benefits of HRT outweigh the possible risk of slightly increasing one's chance of breast cancer, with perhaps the possible exception of women with a strong family history of the disease or other pre-existing risk factors. Interestingly, two feature magazine articles that compared the personal decisions of women physicians yielded inconclusive results; their decisions to take estrogen or not were split for a wide variety of reasons. A few renegade physician-authors with questionable credentials as experts on the subject (e.g., Lee, 1996; Jetter, 1997) have broken ranks from the majority opinion, advising women away from synthetic estrogen replacement. However, one renegade has very good credentials and a wide sphere of influence. Dr. Susan Love, perhaps the breast cancer expert best-known to the public, published a book (Love & Lindsay, 1997) encouraging women away from synthetic HRT, in favor of a diet rich in soy and other natural sources of estrogen. She confirms the validity of fears of increasing one's risk of breast cancer. Critics (e.g., Gladwell, 1997) have strenuously disputed her calculations of probability, leaving the public to choose sides and draw their own conclusions.

***The confusion of self-determination.*** Magazine and newspaper articles did a reasonably good job in explaining the pro's and con's of HRT, emphasizing the difficulties of resolving the dilemma. Very few, directly or indirectly, offered a recommendation one way or another, concluding instead that each reader had to decide what was best for her, taking into consideration her own health history, in consultation with her doctor. The assumption of the National Breast Cancer Coalition and other activist groups is that if women are informed, they can reach their own conclusions. That seems easier said than done. The popular press provided a great deal of information, including contradictory studies about the risk of breast cancer published within a few weeks of one another; schemas for self-assessing one's personal risk of heart, bone, and breast disease; descriptions of designer estrogens that don't deal with immediate symptoms of menopause (in fact, may exacerbate them), but may have long-term benefits; suggestions

to insert "rest periods" during long-term HRT use; even an "optimistic" report that HRT is correlated with breast cancers, but which are slow-growing.

### **Commentary and Revisions in Statement of Work**

To date, two-thirds of Phase 1, the historical overview have been completed, as well as 50% of Phase 2, analysis of current controversies. I shifted prematurely from Phase 1 to Phase 2 due to the sheer exhaustion that I and the research assistant have experienced in reading and coding this amount of material; we needed the relief of doing a slightly different type of work. In addition, a book outline (Appendix B) was developed, as a guide for writing a manuscript from these findings and to begin conversations with potential publishers. A search for completing collection of source materials is ongoing for Phase 3, analysis of breast cancer on entertainment television. Finally, preliminary ideas are under development for Phase 4, the meta-analysis that will conclude this project

As reported in last year's annual report, I remain behind my originally-conceived schedule. Although moving locations during Summer 1998 and changing jobs caused delays, at this point it is clear to me that I also underestimated the time that would be needed to locate, read, and analyze this much print material. I have tried to think of ways to move the project along faster, but have not been able to do so, other than to eliminate the task of comparing mass media reports with professional literature. Thus, in the upcoming year, I think it is realistic to expect completion of Phases 1 & 2, and further work on Phase 4. I hope to have collected or located in video archives source materials needed for Phase 3, but I am doubtful that the television analysis will occur before the funding period comes to an end. As is shown in the book outline, I still intend to eventually complete Phase 3. I will focus on the findings of Phase 2 for presentation at the DOD Era of Hope conference in June 2000.

The study has remained closely tied to its original purpose and research questions that revolve around the issues of the development of a social discourse on breast cancer, the media's influence in shaping a public agenda about this disease, and the implications of media exposure for citizen decision-making. As originally proposed, my analysis has focused on: major themes, language use, the sociopolitical and cultural contexts, media emphases and biases, implicit values and ideologies, appeal to a variety of audiences, and the impact of contradictory arguments and evidence.

### **Key Research Accomplishments**

- Reviewed 427 original popular press source materials in order to analyze the media's depiction of breast cancer during 1976-1985, as it evolved from the previous decade.
- Reviewed 92 original popular press source materials from 1993-1999 in order to analyze and evaluate how depictions of mammography could influence the public's understanding of related issues and personal decision-making.
- Reviewed 83 original popular press source materials from 1993-1999 in order to analyze and evaluate how portrayal of the relationship between hormone replacement therapy and breast cancer could influence the public's understanding and personal decision-making.
- Initiated preliminary formulation of meta-analysis (see Conclusions).

### **Reportable Outcomes**

- Presentation entitled "The Emergence of Patient Choice and Consumer Responsibility: Breast Cancer in Popular Media, 1965-1985" at the International Communication Association, San Francisco, May 1999 (poster format).
- Development of book proposal, based on research findings of this project (see Appendix B). Submitted for review to Lawrence Erlbaum Publishers, who have expressed interest in publication. [Other potential presses will be contacted before any final publication agreement is concluded.]

### **Conclusions**

Looking back at the evolution of the successive and overlapping discourses that brought breast cancer to public awareness--scientific progress, patient choice, medical critique, consumer responsibility--there is a logical progression to an eventual era of heightened activism and sustained politicalization, which we are continuing to experience. Another outcome, prompted by a constant stream of media information concerning biotechnical developments that inevitably offer risks as well as benefits, disappointment as well as hope, is the communication of dilemmas, ambiguity, and confusion.

Contradiction is a common element that is entwined throughout both the historical and contemporary segments of this study. Health care citizens are constantly in a position of choosing between or among contrasting advice of medical experts and enacting authoritative health guidelines that often change, sometimes from one year to the next. Our culture continues to emphasize breasts as sexual and cosmetic objects even as it pays deeper attention to the subjective experiences and effects of breast cancer. The moral and

material successes of breast cancer activism have also contributed to its commodification and perhaps even an incipient degree of backlash. The public face of breast cancer is most often visualized as white and younger, while those hit hardest are older and people of color.

Looking ahead to Phase 4, the meta-analysis, of this project, a number of "so what" issues are implied in this work. Some possibilities to be developed include:

- improving the physician-patient relationship, through more mass media examples of professional-lay partnerships engaged in conjoint decision-making, and sensitizing physicians and other health care personnel to the needs of addressing media information during clinical encounters;
- changing the ways in which results of scientific studies are presented to the public, e.g. as work-in-progress rather than authoritative conclusions, poised for contradiction and de-bunking;
- re-thinking and clarifying the boundaries between citizen participation and responsibility in health care decision-making;
- examining the successes and limitations of breast cancer activism and its impact on other health-related special interests; and
- appreciating how breast cancer as a social issue has changed and improved effectiveness of women's coalition-building and political influence.

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## APPENDIX A



### Content Categories

**A Activism:** Reports on the activities of organizations of survivors and others, trying to raise awareness and money, as well as influencing policies and practices related to breast cancer.

**AT Alternative Treatment:** Therapeutic modalities practiced outside of mainstream, allopathic medicine (e.g., laetrile, variety of pain control techniques).

**BSR Basic Science Research:** reports on laboratory-based research, including cellular activity, viruses, and animal experiments.

**BH Breast Health:** References to breasts in the context of non-cancer discussion. May include such frames of reference as sexuality, aesthetics, nurturance, and benign lumps.

**C Coping:** Descriptions of how individuals have dealt with the problems associated with being diagnosed and ill with bc, and its treatments. Includes most personal narratives (not only people with cancer, but also partners & additional significant others).

**CR Criticism:** Overt or implied disapproval of medical practices, scientific investigation or health policy related to breast cancer

**D Detection:** relates to the identification of breast cancer cells in living humans. Includes writing on the importance of early detection (sometimes referred to as "prevention"), as well as explanations, descriptions of diagnostic technologies, e.g., xerography, mammography, thermography, blood tests, BSE. [reasoning here. "Detection" is a more inclusive word than "diagnosis." For example, a recurrence may be detected.]

**E Epidemiology:** Prevalence or impact of bc on particular sectors of the population, e.g., racial, geographic. Includes environmental factors. Includes non-clinical human subjects research unless the research is specifically concerned with psychosocial issues

**G Genetics:** research, therapy, testing & counseling related to genes & BC [reasoning used here. This begins as BSR, but becomes much more inclusive. Identification of BC gene a major scientific discovery in itself.]

**P Politics:** Association of bc with political candidates, leaders and party platforms. How decisions made on funding bc research and deciding on funding priorities.

**PC Patient Choice:** Discussions related to shifting power relations between the medical community and patients regarding treatment decisions. Includes capabilities of patients to exercise autonomous decisions and partnerships with doctors.

**PA Public Awareness:** Public registering its views about major news events, public figures, media representations related to bc. Issues may include tastefulness regarding privacy/publicity, how public reacts to controversies (eg, surgeries, when to get mammographies).

**PS Psychosocial Factors:** Reports of research and psychological treatments that assumes a connection of personality and mood with breast cancer. Explanations of impact of breast cancer on individual and family dynamics.

Note: Items coded in this category tend to focus on research findings and forms of therapy, rather than individual narratives of coping (C ), e.g., a survey of the prevalence of marital problems for women with breast cancer vs. how an individual with a mastectomy dealt with her husband's aloofness after her surgery.

**PV Prevention:** Eliminating conditions that put people at higher risk for cancer (including specific recommendations for diet and exercise)

**SI Social Issues:** References to breast cancer-related social trends or policy applicable to broad segments of society. May include (but not limited to) precedent-setting legal decisions, social protests, public alerts and warnings, changes in health policy, etc

**T Treatment:** "Objective" (non-narrative?) descriptions of mainstream, biomedical therapeutic procedures, e.g., mastectomy and other surgeries, chemotherapy, radiation. Also includes experimental treatments, clinical trials involving human subjects/patients (comparison among treatments, under scientific scrutiny).

**Table 1**  
**Magazines by Category,**  
**1976-1985**

	B S R	D	G	E	C	P	P C	P S	P A	P V	C R	B H	S I	A	A T	T
<b>Miscella- neous</b>	9	2 2	0	8	9	1	5	1 0	0	2	1	0	1	0	0	2 3
<b>Women's</b>	3	3 1	2	2	1 5	0	1 7	5	2	7	4	1 0	0	1	0	3 4
<b>News</b>	0	5	0	1	1	0	1	0	0	1	1	0	0	0	0	1 3
<b>Total</b>	1 2	5 8	2	1 1	2 5	1	2 3	1 5	2	1 0	6	1 0	1	1	0	7 0
<b>N=186</b>																

**Key to magazines:**

**Women's:** Better Homes & Gardens, Good Housekeeping, Glamour, Ladies Home Journal, Mademoiselle, McCall's, MS., Redbook, Vogue.

**News:** Newsweek, Time, US News & World Report.

**Miscellaneous:** Ebony, Essence, Esquire, Nation, New York Times Magazine, Reader's Digest, Saturday Evening Post, Science Newsletter, Science Digest, Today's Health.

**Key to categories:**

**A** Activism

**AT** Alternative Treatment

**BH** Breast Health

**BSR** Basic Science Research

**C** Coping

**CR** Criticism

**D** Detection

**E** Epidemiology

**G** Genetics

**P** Politics

**PA** Public Awareness

**PC** Patient Choice

**PR** Public Response

**PS** Psychosocial Factors

**PV** Prevention

**SI** Social Impact

**Table 2**  
**Newspapers by Category,\***  
**1976-1985**

	<b>B S R</b>	<b>D</b>	<b>T</b>	<b>A</b>	<b>G</b>	<b>E</b>	<b>C</b>	<b>P</b>	<b>P C</b>	<b>PS</b>	<b>P A</b>	<b>P V</b>	<b>C R</b>	<b>B H</b>	<b>SI</b>	<b>A T</b>
<b>The New York Times</b>	3	46	27	1	0	28	11	9	7	2	5	6	0	2	1 3	1
<b>Chicago Tribune</b>	3	28	21	0	0	23	9	0	3	5	0	9	3	1	5	0
<b>Newspaper Totals</b>	6	74	48	1	0	51	20	9	10	7	5	15	3	3	1 8	1
<b>N=241</b>																

**\*Key to categories:**

**A**    **Activism**  
**AT**   **Alternative Treatment**  
**BH**   **Breast Health**  
**BSR** **Basic Science Research**  
**C**    **Coping**  
**CR**   **Criticism**  
**D**    **Detection**  
**E**    **Epidemiology**  
**G**    **Genetics**  
**P**    **Politics**  
**PA**   **Public Awareness**  
**PC**   **Patient Choice**  
**PR**   **Public Response**  
**PS**   **Psychosocial Factors**  
**PV**   **Prevention**  
**SI**   **Social Impact**

## APPENDIX B

## Visible Scars: Breast Cancer in Popular Media

### Book Prospectus

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**Part I: Introduction** (The largely hidden scar of mastectomy has, for generations, been the symbol of the fearsome disease that all women in Western culture know and dread. Making use of the scar metaphor, the introductory chapter will address the question of why it is important to understand why and how breast cancer has become one of the most visible and discussed aspects of women's health and politics.)

#### **Chapter One. Breast Talk: Culture, Discourse, Breasts and Disease**

This initial chapter will focus on the long history of mixed cultural messages about women's breasts, i.e., maternal/nourishing, erotic, shameful/profane, potentially deadly, and how such messages contributed to the silencing of talk about breast cancer until the latter third of the 20<sup>th</sup> century. Chapter One also will introduce the rationale for studying how breast cancer has been depicted and reflected in popular media, contributing to the development of a discourse about the disease, as well as influencing public attitudes and understanding. Finally, the logic of the book will be explained, and the ensuing chapters briefly described.

**Part II: The Historical Overview** (This portion explores three decades of popular print media portrayals of breast cancer. Using popular magazines and two nationally prominent newspapers, my interpretive analysis takes into account trends in content categories, narrative scenarios played out for the national readership, linkages between breast cancer news and other events transpiring in the larger culture, and the development of rhetorical themes and strategies.)

#### **Chapter Two. The Emergence of Patient Choice: 1965 - 1975**

This chapter traces the development of breast cancer from a minimally addressed subject to a distinct topic of public conversation. Highlighted within this analysis is the rhetoric of scientific progress (a positive framing of scientific and medical advances), increased audibility of first-hand narratives, and attention to patient participation and choice in the treatment of the disease. Attention is paid to how cultural context, including the War in Viet Nam, Presidential politics, women's liberation, and legal decisions about informed consent, helped to shape the newly emerging discourse on breast cancer. This period of time ends with two events that garnered a good deal of media exposure and public attention, i.e., the controversy over whether radical mastectomy should be continued as the state-of-the-art in breast cancer treatment, and the diagnosis and treatment of First Lady Betty Ford.

### **Chapter Three. A Shift from Choice to Responsibility: 1976 - 1985**

Within this chapter, the analysis continues to note the ongoing rhetoric of scientific progress (new developments in chemotherapy, evidence of the efficacy of less invasive surgery), but concurrently demonstrates a deepening critique and suspicion about medicine's role in managing this disease. Following on the heels of the surgery controversy and heightened awareness with calls for early detection, a new controversy arises regarding the safety of mammography radiation: is medical technology protecting women from or exposing them to cancer? A shift in rhetoric begins to occur as laypersons are now expected, not only to have a say in treatment choices, but to assume responsibility for making health decisions in the absence of medical guidelines. Less-than-ideal narratives of well-known women with breast cancer brings the issue of relationships, self-image, and life-after-diagnosis and treatment into greater focus.

### **Chapter Four. The Impact of Advocacy: 1986 – 1995**

Ironically, with the success of alleviating public fear about the safety of radiation and the increasingly widespread employment of mammography, statistics demonstrating an increased risk of contracting breast cancer come to light. Furthermore, a large shadow is cast upon the rhetoric of scientific progress, when it is discovered and publicized that data was falsified by one of the scientific participants in the landmark study that established lumpectomy as an equally safe and efficacious alternative to mastectomy. The characterization of breast cancer as an "epidemic" and those afflicted as "survivors" rather than victims, terminology and tactics clearly influenced by AIDS activists, leads to the emergence of a rhetoric of advocacy. Speaking on behalf of women generally, activist leaders not only work to increase funding toward a cure, but fight to have a role in policy decision-making. This time period culminates in the joining of lay advocates, scientific, and governmental representatives in the development of a National Action Plan on Breast Cancer.

*Part III: Quandaries in Decision-Making* (This portion will deal with popular press accounts in the past five years on four issues that are controversial insofar as medicine and scientific research does not have sufficient evidence to provide definitive advice for individuals. My analysis will deal with the ways in which pros and cons are presented to the public, how epidemiologic generalizations are balanced against individual concerns, and recommendations toward decision-making that are directly offered or indirectly implied).

### **Chapter 5. Mammography and Genetic Testing**

This chapter deals with contradictory information or tensional issues depicted in the popular print media with two forms of screening technologies. Confusion about mammography has been present almost since the inception of its widespread usage in the mid-seventies. As noted in Chapter 3, early on, scientific uncertainty concerning the safe use of radiation technology caused concern and fear among the public. Since then, confusion has ensued about the efficacy of this diagnostic technique in women between the ages of 35-50. Though anxieties about the dangers of radiation have largely been put

to rest, controversy now centers on such issues as when a baseline image should be taken, how frequently—if at all, follow-up images should be done until age 50, and if insurance companies should be encourage to pay for such services in younger women. Genetic testing is a much newer technology that may reveal if women with many cases of breast cancer in their families have a gene that predisposes them to much-higher-than-average risk of contracting the disease (or conversely do not have the gene, and thus may relieve much day-to-day anxiety, especially about passing the gene on to offspring). As with many issues related to genetics generally, testing for the variants of the breast cancer gene may lead to a variety of ethical quandaries, including labeling and exclusion of coverage by insurance companies, and discovery of a potential condition for which there is no cure. The controversial step of “pre-emptive” or prophylactic mastectomy of ostensibly healthy breasts, as a way of reducing potential risk of the disease is currently the only “option” available to people who discover they are positive for the breast cancer gene.

### **Chapter 6. Estrogen Replacement Therapy and Preventive Tamoxifen**

This chapter delves into the presentation of information and arguments for and against the use of two medical treatments that may have positive or negative repercussions for women who consider themselves to be at higher-than-average risk for breast cancer. As with mammography, the use of ERT in menopausal women has a long history of controversy. A long line of scientific studies has yielded a variety of often contradictory findings in regard to whether prolonging the intake of estrogen into women’s bodies puts certain individuals at greater risk for contracting breast cancer. More recently, that risk has been somewhat—though not conclusively—minimized. Concurrently, the benefits of prolonged estrogen intake in terms of other diseases that affect older women—notably osteoporosis and heart disease—have been vigorously argued. Again, women are being asked, in accordance with a physician, but in the absence of individually predictive information, to do their own risk/benefit assessment in order to make this decision. The most recent development in actual prevention of breast cancer is the use of the drug tamoxifen in high-risk, but otherwise disease-free, women. Preliminary studies indicate the drug may prevent breast cancer in women who fear themselves to be at high risk for the disease; at the same time, the drug may increase the risk of contracting other forms of cancer, and other, unanticipated long-term side effects are not yet known. For these reasons, some women’s health watch-dog organizations have opposed the use of this drug in healthy people. In the end, women will need to decide for themselves, in the face of current uncertainty.

### ***Part IV: Beyond the Informative Function of Media***

In this last portion, use of breast cancer content beyond news reporting and women’s features in popular print media will be considered through an analysis of how the disease has been interwoven—some would say appropriated—on entertainment television. This is important insofar as this type of television reaches broad audiences, many of whom would not choose to read about breast cancer in periodicals, or who come to that form of media exposure in a different state of readiness than they would approach a written format. Finally, I will conclude with thoughts about how effectively and/or problematically this



developing discourse has worked, and what kind of impact it has had as a model for future rhetorics of disease and illness.

### **Chapter 7. Breast Cancer as Entertainment**

This chapter explores how breast cancer has been used as content in entertainment television, both historically and especially most recently, with special attention to the serialization of Murphy Brown's bout with this disease. The analysis will explore the two-edged use of breast cancer on television as a venue for entertainment as well as the more "pro-social" functions of education and changing attitudes, using humor and drama as strategies.

### **Chapter 8. The Rhetoric of Breast Cancer**

In this final chapter, I will assess the importance of breast cancer as a "representative anecdote," an instructive case study for both effective and not-so-effective public discussions of illness, medical advances and uncertainty, and collective advocacy and responsibility. I will especially focus on "take home lessons" for the public readerships and viewerships of popular media.